ALASKA TRAUMA REGISTRY RELEASE OF INFORMATION POLICY

INTRODUCTION

The purpose of the Release of Information Policy is to establish guidelines for the release of data from the Alaska Trauma Registry to individuals or organizations requesting information. In sharing trauma registry information it is the intent of the Trauma Registry Review Committee that

- 1) patient, facility, and service confidentiality be protected
- 2) legitimate and responsible use of trauma registry data for the purposes of promoting research, education, injury prevention, and peer review be insured, and
- 3) trauma registry data be represented accurately and without prejudice to an individual or institution.

PROCEDURE

Information requests will be put into one of four categories and considered as outlined below.

- 1) Participating trauma registry hospitals and ambulance services will receive four quarterly reports as has been established by the Trauma Registry Review Committee. Customized reports or information will be provided to a individual or institution requesting information pertaining to themselves.
- A recognized and known legitimate individual or organization requesting non-privileged data or information from the trauma registry for the purpose of promoting research or education will be provided the requested information by the Trauma Registry Coordinator. Privileged data or information is defined as any data or information identifying an individual patient, physician, hospital, or prehospital care provider, and acquired in the performance of activities of the Alaska Trauma Registry program. The Trauma Registry Coordinator may require that the requestor submit his/her request in writing and provide proof of requester legitimacy.
- A request by an unknown individual or organization or a request for privileged data may be reviewed by a subcommittee of the Trauma Registry Review Committee, called the Release of Information (ROI) Subcommittee. The requester is required to submit to the ROI Subcommittee a completed Research Application form along with a copy of his/her study proposal, if applicable.

Release of information may be contingent upon any or all of the following:

- a) Reimbursement of costs of services
- b) Ownership of the data will remain with the Alaska Department of Health and Social Services, Division of Public Health, Section of Community Health and Emergency Medical Services

(ADHSS/PH/CHEMS).

- c) Access to the data file will be protected by a security system that requires the user to provide at least one password.
- d) Release of non-aggregate data to any other individual or agency without the express permission of the ADHSS/PH/CHEMS Section is prohibited.
- e) The recipient will commit to protecting the identity of trauma registry patients, ambulance services, and hospitals. (Although we do not give names, the community name, dates, age, sex, and race are sufficient to identify an individual or service or may be identified through data linkage.)
- f) The recipient will submit to the ADHSS/PH/CHEMS Section a signed Alaska Trauma Registry confidentiality statement.
- g) The data may only be used for public health research, education, or program planning or evaluation.
- h) The recipient will allow the ADHSS/PH/CHEMS Section and the Trauma Registry Review Committee a prepublication review of conclusions based upon data from the trauma registry. (This is to insure correct interpretation of the contents of the database.) If disagreement exists, the recipient will allow the Trauma Registry Review Committee the opportunity to include their comment within the published document.
- i) Acknowledgement is to be given to the ADHSS/PH/CHEMS Section as the source of data in any publications, articles or studies that are prepared or published.

STUDY PROPOSAL

The study proposal will include objectives, methods, study population of interest, and specific elements needed from the trauma registry. The requestor must inform the trauma registry ROI Subcommittee of any changes to the study design or changes in the estimation of time for project completion.

DUTIES OF THE TRAUMA REGISTRY REVIEW COMMITTEE

The Trauma Registry Review Committee will appoint a Release of Information (ROI) subcommittee consisting of at least one physician. The ROI Subcommittee will be available to make final determinations on requests for information from the trauma registry. An information request review by the ROI Subcommittee may be accomplished by circulation of the proposal to subcommittee members.

DUTIES OF THE TRAUMA REGISTER COORDINATOR

The trauma registry coordinator will:

- 1) Prepare quarterly and custom reports to participating hospitals
- 2) Answer legitimate requests for non-privileged data by recognized individuals
- 3) Reject inappropriate requests
- 4) Work with requestors and ROI Subcommittee members on requests that fall into category #3 above
- 5) Report all information requests to the Trauma Registry Review Committee during quarterly meetings by presenting short summaries of information provided.

RESEARCH APPLICATION (To be filled out by applicant)

AGENCY OR INSTITUTION:	NAME:	
ADDRESS: TELEPHONE: PROJECT TITLE: EXPECTED TIME OF COMPLETION: Please attach a copy of the study proposal: objective, methods, study population of interest specific elements required from trauma registry. (To be filled out by the Trauma Register Review Committee, Release Of Information Subcommittee)	POSITION:	
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Please attach comments.